

Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world

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Accepted for publication

15 June 2009

Keywords: Arnstein, English NHS, globalization, health policy, patient choice, patient rights

Abstract

Background Changing the relationship between citizens and the state is at the heart of current policy reforms. Across England and the developed world, from Oslo to Ontario, Newcastle to Newquay, giving the public a more direct say in shaping the organization and delivery of healthcare services is central to the current health reform agenda. Realigning public services around those they serve, based on evidence from service user's experiences, and designed with and by the people rather than simply on their behalf, is challenging the dominance of managerialism, marketization and bureaucratic expertise. Despite this attention there is limited conceptual and theoretical work to underpin policy and practice.

Objective This article proposes a conceptual framework for patient and public involvement (PPI) and goes on to explore the different justifications for involvement and the implications of a rights-based rather than a regulatory approach. These issues are highlighted through exploring the particular evolution of English health policy in relation to PPI on the one hand and patient choice on the other before turning to similar patterns apparent in the United States and more broadly.

Conclusions A framework for conceptualizing PPI is presented that differentiates between the different types and aims of involvement and their potential impact. Approaches to involvement are different in those countries that adopt a rights-based rather than a regulatory approach. I conclude with a discussion of the tension and interaction apparent in the globalization of both involvement and patient choice in both policy and practice.

Introduction

Contestation over the desire to involve the public more directly in the evaluation and development of public sector services has a long

history. A key hierarchy of involvement was developed by Arnstein almost 30 years ago.¹ She proposed a 'ladder of citizen participation' with the lowest rungs identified as activities that informed or consulted the public about potential

changes, while at the apex of the ladder the power to decide what changes were made was reserved for the public. The starkness of Arnstein's framing of citizen participation as an overt struggle for power, between public sector managers and public activists and community members, continues to have resonance both in planning actions and explaining conflict but fails to engage with the complexity and nuances of patient and public involvement (PPI).

A number of scholars have applied and reinterpreted Arnstein's ladder over the last four decades. Wilcox² developed a five-rung ladder while Burns' ladder of citizen empowerment attempted to incorporate degree of participation and quality of engagement.³ Only Choguill's adaptation, for use in 'underdeveloped countries', considers explicitly the potential for organizations to exert a negative influence.⁴ Despite the interpretations, refinements and revisions of Arnstein's model, they retain a similar 'hierarchical approach', and uncritically embrace citizen control as the ideal form of involvement. These approaches, like Arnstein's, fail to capture the complexity of involvement. Similarly, the diversity of the actors in involvement, the importance of process as well as outcome, and the integration of a systematic approach to engagement and feedback are all lacking in these models. Also they tend to assume that power differentials between institutional and non-institutional actors are unreflexively replicated. Most importantly, they assume that power is finite and that ceding power to one or other parties diminishes the power of the other rather than considering that there are different kinds of power and knowledge and that partnership and collaboration can bring about a better outcome.⁵ In this context, the continued salience of ladders of involvement is not simply an artefact of limited theoretical development, but more the continued unwillingness by public sector managers to make involvement more than a 'tick-box' activity. The increasing policy pressure to undertake PPI is reinforced in England by the National Health Service (NHS) target culture but rarely is examined in a way that ensures that involvement has an impact on

organizational policy, healthcare practice or professional cultures.

There are different reasons for involving patients and the public in health services. Individual patient participation in *treatment decisions* is one category, but is distinct from involvement in *service development*, or the incorporation of user views in the *evaluation of services*. The *education and training* of health professionals has long relied on patients participating in teaching and training through testimonials about their own experience and, more recently, through participation in curriculum development. Increasingly patients and the public are being asked to engage in all aspects of the *research* cycle. Clearly, there are interactions and linkages between these five different categories of PPI. For instance, service development may have a direct impact on the range of individual treatment options that exist, and service evaluation may identify inequities in access that affect individual participation in treatment.

Terminology is problematic. Throughout this article I have adopted the term 'patient and public involvement' and defined it to mean 'Ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organization and delivery of health services'. This definition incorporates the five different types of involvement I have set out in the previous paragraph. I acknowledge that terms such as user, carer, consumer and engagement are also used in these debates but all are contested and have adopted the term most dominant in the European policy debates. I differentiate between the types of involvement because they require different methods, have different aims and often engage with different types of people to influence different aspects of organizations or policy.

Direct and indirect involvement

The vast majority of involvement activity in health care is *Indirect involvement* and typically entails information gathering from service users by health professionals and managerial staff in order to inform service delivery and

development. While the views of people (patients and the public) are sought, health service managers and clinical staff make the final decisions. Staff can choose to ignore feedback from people if they think it inappropriate, or decide what aspects of the information they have collected they should take into account. *Direct involvement*, by contrast, is based on patients and the public taking part in actual decision making. This includes determining the services that are offered and how resources are used. The distinction I am drawing is different from that made by Harrison *et al.* who see indirect involvement as the views of service users or members of the public are mediated 'through an agent, such as an elected representative or an allocated advocate'.⁶

As well as the five categories of involvement suggested earlier in the article (treatment decisions, service development, evaluation of services, education and training or research) and the distinction between direct and indirect approaches, a further distinction can be drawn between those activities that are aimed at individuals and those that are premised on collective participation (see Fig. 1). For individuals, an example of direct involvement might be choosing to have a particular procedure, or choosing not to have chemotherapy. Collective direct involvement might be involving a breast cancer support group in designing a new breast cancer clinic in a local hospital. In each of these cases the involvement activity includes the power to participate in making the decision.

Examples of indirect involvement at the individual level include making a complaint or providing input about a positive experience of care. At a collective level indirect involvement might be a report submitted by a patient support group about their recommendations for service improvement. In all these cases the involvement activity generates information, but the decision to

act on the information, and indeed what aspects of the information to take into account, is retained by the health professional or manager.

Proactive and reactive involvement

A final element of this conceptual model of involvement relates to the extent to which involvement activities are prompted. Many health organizations have recognized that developing and supporting user groups is beneficial in generating relevant intelligence on service design, and helping to target resources and services to the needs of the local community. Such groups, whether they are as a health or citizen panel,^{7,8} or involvement forum,⁹ will operate in different ways. The health organization is likely to seek users' views on plans or documents and send them to the group for review and feedback. Other organizations may ensure that the user group has representatives on the Board of the organization and that there is a standing agenda item at every meeting that creates an opportunity for the group to raise issues that require a response.¹⁰

The model I am proposing provides a framework for differentiating the aim of involvement activities (treatment decision making, service evaluation, service development, education and training and research) in relation to the three dimensions I have identified: direct – indirect; individual – collective; proactive – reactive (see Fig. 2). That is the model takes in to account the degree of direct decision making that participants are delegated, the extent to which participants are acting as sole agents or as part of a group, community or population and the degree to which their participation is responding to a pre-existing agenda (reactive) or is helping to shape it (proactive). The model presented here corresponds to the work of Oliver *et al.* but extends it beyond the boundaries of involvement in research.¹¹

Individual direct	Individual indirect
Collective direct	Collective indirect

Figure 1 A matrix of involvement.

	Direct		Indirect	
Individual	Proactive	Reactive	Proactive	Reactive
Collective	Proactive	Reactive	Proactive	Reactive

Figure 2 A model of involvement.

Evaluating patient and public involvement

There is an assumption that PPI is a 'good thing'^{12–14} and research findings have found broad-based support for such activities.^{15,16} As has already been suggested this is in part due to the different categories of PPI; physicians may accept the legitimacy of patient participation in decision making but not in the prioritization of services.¹⁷ More importantly there are differences in the acceptance of PPI that are related to professional roles: 'professional responses can partly be understood in relation to specific occupational standpoints and strategies that potentially allow professionals to define and limit users' involvement'.¹⁸ In other words, despite apparent acceptance of the value of involvement, the different professional roles, responsibilities and orientations to health care influence the acceptance of the legitimacy of PPI in terms of service user evaluation and development and may limit the categories of involvement that are supported.

This mixed response to PPI is in part due to the lack of evidence of the positive impact of involvement despite the apparent commitment to involvement in principle. As Arnstein noted almost 30 years ago, 'The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you'. Involvement is assumed to promote self-efficacy, develop social capital and create accountability but there is little published evaluation of the impact that involvement activities have made on those involved or the delivery, or outcome, of healthcare services.^{13,19} As an international review of the literature linking involvement to quality in health care concluded:

The public (patient/patient groups) have contributed to the planning and development of health care services across a range of different service areas and levels and in many different countries, but the impact of this involvement on the quality and effectiveness of health services is undetermined.²⁰

This was reiterated by Crawford *et al.* in their systematic review of the PPI literature, although the authors noted that this was in part because

most published work on involvement focused on the experience of being involved as an outcome, rather than the impact on services or patient outcomes.²¹ However, it is worth highlighting that much of the published evidence relates to involvement activities in mental health and cancer services. Both of these conditions tend to have long-term implications, rely on patient self-management and disrupt people's lives significantly.^{22,23}

There have been a number of attempts to consider how to evaluate the impact of involvement activities.²⁴ For example, in the UK the Welsh Assembly produced *Signposts* and *Signposts Two* as guides to support the development of PPI in health organizations. The guides are typical of the existing approaches to evaluating PPI and include ways to benchmark and evaluate PPI activity and self-evaluation tools 'to assess how far your organization has progressed in its development work on building capacity for effective PPI'.²⁵ The weakness of this self-evaluation tool is that there is no requirement to provide evidence to justify whether the evaluation fully, partly, or fails to meet the 91 different criteria – 14 of which focus on the Results and Impact of PPI activity.

A more useful approach to evaluation was developed by the Surrey and Sussex Strategic Health Authority in the UK.²⁶ This identified 58 'actions' that needed to be taken across eight dimensions and 16 competencies, including 'Ensuring PPI has an impact', 'Partnership working' and 'Patient information'. For each 'action' a position statement is sought with evidence to underpin the statement and this is assessed in terms of red, amber or green status. This was designed to complement the Self-Assessment declaration around PPI (Core Standard 17) that forms part of the regulatory procedures undertaken as part of the UK Healthcare Commission's Annual Health Check.²⁷

Policy pressures

Individual patient decision making is the dominant type of involvement in relation to policy. As previously noted, PPI in terms of

patient-centred care and treatment decision making has been an integral part of the *new medical professionalism* that has been presented as a changed relationship between physicians and patients.²⁸ This concentration has also created a perceived connection between PPI and patient choice. The other types of involvement, generally relating to collective forms of engagement, are apparent in policy primarily in relation to policies that support greater accountability and evaluation and are therefore retrospective such as annual patient surveys. The involvement of patients, the public, citizens and taxpayers has generally been framed either as patient's or human rights or in terms of regulatory requirements on publicly funded health planners and providers. The latter framing often takes the form of involvement to demonstrate that patients and the public have been consulted around the closure of a hospital or emergency room.

Justifications and definitions of user involvement in public services range along a continuum between democratic and consumerist models.^{29,30} Typically, the distinctions relate to rights inherent in citizenship vs. those of individual choice in the marketplace. The complexity of the tensions between these two very different positions is apparent in the ways that competition between service providers, patient choice and complaints are often framed as involvement. The implication of such tensions is the redefining of the relationship between the state as the guarantor of the health and well-being of its citizens and the state as the promoter of markets and consumerism. As Ignatieff has asserted

It is a symptom of the crisis of citizenship...that most political rhetoric, whether left or right, addresses the electorate not as citizens but as taxpayers or as consumers. It is as if the market were determining the very language of political community.³¹

In this sense, the aim of user involvement and the methods used to engage users can only be understood in relation to the relative primacy of one or other of citizenship or consumerist justifications. Individuals will be involved in different ways if the aim of the interaction is consumption and choice rather than the promotion of

accountability for the prioritization and pattern of service provision to the community that is being served.

The pressure to promote local involvement as part of implicit and explicit policy is also driven by the patterned decentralization of health services that is apparent across Europe. The rhetoric of greater involvement of the public in shaping public services has been described as *mimic consumerism*.³² The reframing of a healthcare system that is predicated on services free at the point of delivery that aim to limit inequality has consequences not only for the definition of the patient and service user but also for governance and accountability to the public. In part this highlights the tensions between involvement and consumerism which are particularly apparent in relation to individual action.

Patient-centred care is typically predicated on creating opportunities and responding to a patient's desire for information and participation in treatment decision making in a medical consultation. The evolution of patient-centred care has been broad based although the impact on practice or patient experience has been mixed.³³ As Stewart has observed,

Patient centredness is becoming a widely used, but poorly understood, concept in medical practice. It may be most commonly understood for what it is not – technology centred, doctor centred, hospital centred, disease centred. Definitions of patient centred care seek to make the implicit in patient care explicit.³⁴

The policy response to shifts in public expectation, and questioning of traditional power relations between patients and health professionals and between the public and the public managers with responsibility for publicly funded health care, has been of two main types: placing statutory duties to involve people on publicly funded providers of healthcare services or the establishment of patient rights.

This process is particularly apparent in Britain, where

...citizenship is confused with consumerism and democracy with marketing. Choice and individualism are elevated to the status of moral

imperatives. ...The consumer is characterized not only by the right to choice but also by entitlement to redress.³⁵

In Britain, PPI can be traced back to the establishment of Community Health Councils in 1973, but the involvement project has received far more attention since 1999 with successive legislation and policy.^{36–42} This reform agenda has increasingly elaborated the specification and responsibilities of publicly funded health providers to demonstrate that they have engaged the public and patients about the evaluation, change and development of health services.

The degree of user involvement in other OECD countries varies but it seems at least as dependent on the historical development of law and policy as on the nature of the health system. Resistance in the United States to collective-based health care is in part because of the legal framing of individual and patient's rights but also the limited nature of the broader welfare state. Further the dominance of consumerism and the complex regulatory environment defined by the division of powers in a federal system creates significant variation among states, thereby weakening the rights-based legal claims. Developments in the Netherlands, for example, have been more systematic, with a greater emphasis on legislation than those in the UK.⁴³ Denmark, like the other Nordic countries, involves patients and the public in the running of the health service through local democracy. In addition to the patients' rights and complaints systems that exist in most Nordic countries, patient organizations contribute actively to health service development and debate.^{44,45} By comparison, in Sweden and Finland, involvement is more passive and largely exercised through local elections.⁴⁶ Despite the long history of acclaiming the importance of user involvement in Canadian health services, representing them as a continuum rather than a ladder, the legitimacy of many exercises continues to be challenged. Current Canadian structures are similar to those in England with an emphasis on competent citizen governors, public reporting of performance, and various mechanisms to ensure that patients can access care and have

their complaints addressed. The Romanow Commission proposed developing citizen involvement in the policy development process and strengthening accountability between citizens and policymakers.⁴⁷ However, insufficient political will and tensions between national and territorial governments seem to have blocked subsequent implementation.

Legal drivers

Rather than the structure of the healthcare system, the nature of national law and policy has significant implications for the emergence and development of PPI. Typically law takes two forms: rights-based or regulatory. A range of countries have enacted rights legislation that explicitly define patient rights or indirectly do so within the broader context of human rights. In 1992, Finland passed what it claimed was the first law specifically on patients' rights – The Act on the Status and Rights of Patients (785/1992). In 1994, the WHO Regional Office for Europe hosted a European Consultation on the Rights of Patients in Amsterdam. Drawing a distinction between individual patient rights and the responsibilities of the state to residents and social patient rights, the final report suggests

Social rights in health care relate to the societal obligation undertaken or otherwise enforced by government and other public or private bodies to make reasonable provision of health care for the whole population. ... Social rights also relate to equal access to health care for all those living in a country or other geopolitical area and the elimination of unjustified discriminatory barriers, whether financial, geographical, cultural or social and psychological.¹⁰

Most legislation when discussing patients' rights, frames them in terms of individual rights.

individual rights in patient care are more readily expressed in absolute terms and when made operational can be made enforceable on behalf of an individual patient. These rights cover such areas as the integrity of the person, privacy and religious convictions.¹⁰

The alternative approach to safeguarding opportunities for patients to access health

services in a just and equitable manner makes use of regulatory power. England, for instance, relies on formal regulators such as the Healthcare Commission, the National Institute for Health and Clinical Excellence and statutory instruments to direct healthcare providers to achieve these goals.

These different approaches imply a 'primacy of the individual' in countries adopting a patient rights model, and the opportunity to ensure a degree of 'collectivism' in those countries, such as the United Kingdom that utilize a regulatory approach. This distinction is further reflected in orientations to key policies such as 'patient choice' that also promote individual level action in the pursuit of individual health benefits. Sweden, for instance, has been pursuing a patient choice agenda since 1998.⁴³ Here, implementation of 'choice' has accelerated significantly since the Moderate Party-led alliance took power in March 2007 and embraced a conservative-led agenda privatizing health services.

At the European level this tension is also apparent as illustrated by the development of a Health Service Directive of the *European Parliament and of the Council on the application of patients' rights in cross-border healthcare*.⁴⁸ In relation to the patient choice agenda the draft Directive seeks to

allow patients to seek any healthcare in another Member State that they would have been provided at home and reimbursed up to the amount that would have been paid had they obtained the treatment at home, but they bear the financial risk of any additional costs arising.⁴⁶

This directive seeks to clarify opportunities for patient consumerism and therefore reinforces trade and commodification of health services across Europe but is framed, as is indicated by the title, within a rhetoric of patient rights. By promoting the free movement of patients but retaining the responsibility for payment to the home country the directive seeks to create competition at least in part on the basis of price between countries. It also undermines the scope for individual countries to manage the fixed resources invested in a health system. In some

sense this also reflects broader global trends in health tourism and the willingness of people to travel internationally for health care, a trend also apparent in the United States.⁴⁹ Sometimes medical tourism is framed in terms of seeking quality but as often it relates to elective interventions and a desire for privacy and expense; examples range from a rhinoplasty and safari in South Africa or Swedish patients travelling to Estonia for dental implants.

The English Department of Health too, is in the midst of a consultation on a new NHS Constitution which, like the Patient's Charter 15 years ago, also draws on a rights-based discourse without granting any new legal entitlements – although debate over the Health Bill 2009 which enacts the Constitution, may change this. Throughout the Constitution a language of rights is used to frame aspirational statements about health. Such a discourse is best understood within the broader construct of a changing relationship between the state, patients and the public that, in part, draws on 20 years of neo-liberal inspired health reforms whilst also stressing the potency of involvement.⁴⁴

These different frameworks within which patient choice is articulated have consequences for PPI. A rights-based approach often builds on existing human rights legislation or treaties and frames appropriate access to services as an individual entitlement. Associated with this entitlement are the consequential requirements for access to information and justice without which competition would not be possible.⁵⁰ In contrast, a regulatory approach places requirements on those who plan, fund and provide health services.

For a regulatory approach, PPI can be integrated into the requirements around planning, evaluation and delivery of services. Patients and the public can be involved in the training and appointment of healthcare professionals and the generation of evidence (involvement in research). For a rights-based approach it is far more difficult to require involvement in processes of planning and delivery as patient involvement is defined as the 'active', 'conscious' choosing of some services over others. From this

perspective, public involvement is simply the aggregation of individual decisions. This distinction in the framing of the nature and role of PPI suggests different conceptions of the relationship between the state and the citizen. Similarly, the 'public' is a category and not a collective.

Involvement and choice in the English NHS

Engaging the public has a long history in the NHS often traced to the founding of Community Health Councils in 1973. Since 2001 this has accelerated with a series of pieces of legislation that have reinforced this agenda and created different models to support PPI. Most importantly these laws have created a duty on those who commission and provide publicly funded health and social care service to show how they have engaged with patients and the public in the evaluation, development and delivery of services.

The establishment and roll-out of NHS Foundation Trusts has created the potential for stronger connections between hospitals and their local communities. Whilst remaining firmly part of the NHS, their Board of Governors is elected by the public, patient and staff members and can serve as a vital conduit for shaping the way local services are provided and increasing the credibility and responsiveness of Foundation Trust hospitals through advising the executive board. Thus far, however, there is insufficient evidence that this potential is actually reflected in practice. Equally, there is little evidence that Foundation Trusts do create, promote or react more to a dialogue with the communities they serve than their predecessors.^{51,52}

The time, skill and energy that members of Patient and Public Involvement Forums (which replaced Community Health Councils in 2003) have put into improving health services has, in some communities, had a significant impact. But too often Forum members did not accurately reflect the views of their local community or communicate with those they were intended to represent.^{53,54}

The NHS has just witnessed the launch of local involvement networks (LINKs) in 152

Local Authority areas across England. This new model for involvement, a function of the Local Government and Public Involvement in Health Act 2007, is based on the interaction between networks of local community and voluntary organizations and interested people within a defined local authority area. These LINKs are charged with bringing together the experiences and expectations of local people to evaluate and improve local health and social care services. They are not an inspectorate but a source of intelligence about what the experience of service users, and what the priorities for health and social care services should be. The power of LINKs to influence change is particularly apparent in their role in commissioning local services; the process of prioritizing and contracting for service provision. Ensuring that LINKs intelligence reflects the diversity of the local population is vital, as is using a range of methods to capture people's views, experiences and expectations. This approach is a significant shift from previous approaches to involvement but the strengthening of opportunities for PPI is even more surprising in the context of the long-term commitment of the UK government to the patient choice agenda.

Although a high profile focus on patient choice has been readily apparent in the United Kingdom since 2003, in implementation terms, the operationalization of individual choice has been limited and mostly focused on England (rather than Northern Ireland, Scotland and Wales).^{36–38,40} For example, the *Choose and Book Scheme* enables patients at registered General Practices who are referred for secondary investigations and treatments to 'choose' between four options. These options are all different acute hospital trusts. To enable patient choice, information is provided on (1) the distance to the hospital, (2) the waiting time at the clinic to which the patient is being referred and (3) parking arrangements. Thus, the 'choice' is solely a function of location. There is no scope to specify the physician or the particular intervention (e.g. type of surgical procedure). The patient can separately look up the national evaluation of the hospitals they are offered

which will include independent treatment centres but these ratings are not readily available at the initial discussion. The proposed personal health budgets announced in the Health Bill 2009 further develops consumerism and patient choice in England by piloting a mechanism aimed to enable people to 'spend' resources allocated for their health care.⁵⁵

Such policy initiatives are part of the broader promotion in England of PPI, as well as patient choice through marketization and increased competition within health care. Initially this was driven by a desire to contain healthcare spending, produce cost savings, and increase fiscal efficiency. However, when the Labour government came to power in 1997 it chose to invest significant extra funds in to the NHS; NHS expenditure rose from £34.7 billion in 1997–1998 to a planned £92.6 billion in 2007–2008.^{56,57} The continued promotion of markets was no longer based on limiting healthcare expenditure, but rather on producing higher quality services through competition. Since the change in Prime Minister, the Brown government once again shifted the justification for markets and competition with the intention of aiming to generate 'localization', or services that respond to the needs of local communities. The changing rhetoric used to justify a common policy approach has driven the continued evolution of healthcare markets in England; both patient choice and involvement continue to be tied to this agenda.

The challenges of the globalization of involvement and choice

We may be seeing the emergence of a new phase of health reform as policies promoting patient and public voices in healthcare gain prominence across the OECD countries.⁵⁸ Such a policy trend is mediated by the historical evolution of national health policy, medical culture and definitions of what it means to be a patient or an active citizen. At the same time pressure to contain the costs of health care continues to lead policy makers to seek solutions inspired by markets that reframe patients as consumers. This is particularly apparent in the tensions

inherent in the Obama healthcare reforms. The proposed reforms are based on eight principles aimed to guarantee access and bring down costs while also ensuring individual patient choice of provider, and not limiting business opportunities but rather making the central government the insurer of last resort for catastrophic illnesses.⁵⁹

PPI emphasizes dialogue between communities and those who plan and provide health services. The relevance of this dialogue is based on the expertise that the experience of health care brings to improving the quality and organization of health services. Further, it creates an accountability mechanism by expecting the justification for what and how services are provided in relation to the needs of the local community and their expression of those needs. There is a danger that patient choice is presented as a form of involvement and the aggregation of individual patient choices becomes a proxy for the involvement of patients and the public in a community.

The resurgence of patient choice, often presented as a form of patient empowerment, is striking particularly as there is little apparent pressure from citizens for increased choice. Survey evidence from the Nordic countries, where this policy agenda is accelerating dramatically, highlights critical attitudes towards commercialization and support for publicly financed health services. Findings from a recent WHO survey on responsiveness in health care documented that only 3% of Swedes and 6% of Finns considered choice as the most important aspect of non-clinical care; prompt attention, dignity and communication were far more important to respondents.⁶⁰ While it is reasonable to expect that some choice should be accommodated within health systems, the emphasis on patient choice as a steering mechanism, or fundamental principle, is problematic.

An emphasis on patient choice may undermine population-based approaches to public health and health policy. As health services are increasingly out-sourced to create competition to promote efficiency and improve quality, health systems enter more deeply into a new regulatory context. This direction of travel has

implications for fragmentation, continuity of care and – particularly for people with long-term conditions – the quality of care. In this broader framework the task of regulation on the basis of health policy priorities, principles and values, such as equity, solidarity and universality, becomes more challenging.

The narrowing of involvement and accountability to an emphasis on patient choice as the primary means of empowering patients is problematic. The proponents of patient empowerment are now as likely to come from the corporate think tanks and employers associations with visions of a ‘win-win’: situations where low public costs are combined with patient choice and more individualized financing of health systems accommodating better mobility within nations and across Europe and globally. Proponents of patient choice use the language of rights but there is confusion in terms of what these different rights imply. Health systems are needs-based, not structured around ‘wants’ and must always at least indirectly engage in the rationing of resources. Social rights such as equality of access underpin the social and collective context in which health systems operate as well as the basis of their function.

Conclusions

PPI has emerged on the health policy scene as a response to a series of tensions – individual/collective; consumerism/patient-centred; rights/regulation – and is being adopted for diverse reasons from cost-containment and shifting responsibility to better tailoring of services to meet the needs of patients and communities. Despite this contestation of ends, PPI holds the potential to redraw not only the relationship between those who provide health care and those who use these services, but the culture of health services and the position and responsibility of the state.

Resistance to involvement policies sometimes takes the form of assuming that activated individual patient choices can be aggregated and take the place of collective involvement. Further

concerns about the time and resource requirements needed to develop the relationships and trust to provide a basis for holistic and responsive local health economies are also presented as limitations to PPI.

The development of healthcare markets, particularly in countries with publicly financed and publicly provided healthcare services, has its roots in broader global pressures and proffered policy solutions that are tied to international organizations such as the OECD, World Bank and World Trade Organisation that directly or indirectly influence the organization, regulation and policy frameworks of healthcare systems. Policy transfer is very clearly apparent in relation to the development of both patient choice and PPI but so too are the efforts of the global healthcare industry to influence policy at a national level. Healthcare reform around the world has embraced new public management, neoliberal thinking and marketization to change the justification and mechanisms that drive service development and reform at a local and national level as has been particularly apparent in the UK.^{61,62} But the pressures of globalization towards particular forms of commercialization of health care can be resisted even when they appear to reinforce the domestic interests of industry as well as some politicians and political parties.⁴⁴

Markets in health care require consumers and a range of policy instruments have been used to ‘empower’ patients and transform them from recipients of local services to expert shoppers.

The ‘good consumer’ of health care is compelled to make choices, to exhibit appropriate ‘information-seeking’ behaviour, and to behave in certain prescribed ways (consulting ‘relevant’ expertise, taking the ‘right’ medicine, engaging in personal risk management, and so on).⁶³

The U.S. context is one that has embraced a marketized approach to health care but in which individual choice has long been circumscribed by either personal wealth or the requirements of health insurers. Current proposals for health reform championed by powerful healthcare industry lobbyists seek to guarantee individual choice and seek to define this as an entitlement. Within weeks of President Obama announcing

that key private stakeholders in the healthcare industry would cooperate with the reform of the U.S. healthcare system both the insurance industry and the hospital association were actively lobbying against any change.⁶⁴

Patient choice is the mechanism that is being used to try to promote individual consumerism in health systems. The consequences in terms of shifting responsibility, inequality and opportunity cost are significant.

Building an engaged community takes time and a track record of success. Creating a dialogue that shares problems, identifies limitations and embraces innovative solutions is essential and requires courage. Those who manage our public services have to trust the people to be reasonable, to understand the trade-offs that are an inevitable part of budgeting, and explain that change takes time as well as motivation and good ideas. Open and transparent communication about how the views of the people have changed service design and provision are vital to create a track record that builds trust and legitimacy and a motivation for involvement. The potential to create a health system that maximizes health gain for all and is founded in the experiences of people and patients and their involvement in shaping healthcare policy and practice requires us to contest the need for individual consumerism and patient choice. The interests arrayed to promote marketization and re-define involvement as consumerism may limit the evolution of PPI as an integral part of health systems and prompt revolution.

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